NDIS: The only way out

We have a daughter, Laura, who developed a severe form of autism between the ages of two and three, and will turn 21 in June.

When Laura became disabled, she was violent towards herself and others, and at times would scream for hours on end. She was extremely sensitive to clothing, and got to the stage where she refused to wear any clothes whatsoever. Any attempt to get her to wear clothes led to “tantrums” that lasted as long as we or anyone else tried to keep the clothes on her. At this time her 5 year old brother and sister who had not turned two were hiding under their beds in fear.

Despite desperate attempts, including direct contact with the ACT Minister for Health (as we were living in Canberra then) we could not access any services that could help Laura with her problems. As a result, for the sake of our family we felt we had no option but to admit Laura to hospital, where she stayed, with no clothes, for 3 months (see attached article from the Canberra Times).

During Laura’s time in hospital, we had arranged at our expense (requiring us to take out a second mortgage) for a specialist in the behavioural and educational treatment of children with autism to come from Western Australia to set up an intensive program for Laura. After some determined lobbying, the ACT Government agreed to carry on this program, though it lost a good deal of its focus after the specialist left. Laura was moved into a Government-owned house where her program continued, and she soon started wearing clothes again. She returned home a couple of months later.

After some months Laura’s program was wound down and she started going to a special school, but in her second year there she was rapidly going back into crisis. She was stripping off her clothes at school and had been suspended from the school bus. We withdrew Laura from the school, but still could find no remotely appropriate placement for her in the ACT. At this point, we were lucky enough to receive an invitation out of the blue to apply for a place for Laura at Giant Steps Tasmania, one of a few centres in Australia with the expertise to conduct programs for children severely affected by autism. We moved to Tasmania to take up this placement, even though we had to uproot ourselves from family and friends, and the move led to a major, permanent loss of income and career prospects.

Laura is still at Giant Steps Tasmania – now in the newly developing adult program. Although she still has many problems and will continue to need lots of support, she is mostly happy, has loads of character, and has developed skills in areas such as artwork, dancing and cooking that we never thought possible.

Over the years we have had to fight hard for the funding to keep Laura at Giant Steps, as this has been reviewed every year, until last year we finally received an undertaking that Laura’s funding would be ongoing.

What Laura’s story tells us is that the services for disabled children – and adults – in Australia are grossly inadequate. In many cases the services simply don’t exist, and need to be created from scratch. In recent years there has been encouraging progress in developing early intervention programs for children with autism. However, when these children grow into adults, services are still few and far between or non-existent, especially for those at the severe end of the spectrum.

This lack of services has been brought home to us again in the case of our other daughter, Joanna, who has recently been diagnosed with Asperger's syndrome. Having Asperger's, Joanna has great difficulty dealing with other people, and with the practical matters of everyday life. She would really benefit from having a life skills coach, but we have not been able to find one.

The serious implications of the shortage in services become evident when we see the situations faced by other families with disabled children. It isn't fair that many families don't get help because they simply can't afford it; or because they don't have the skills, time, energy or family support to fight their way through the disability system. It isn't fair that many parents have to give up work and can never take sufficient time out from their caring responsibilities.

The only way this lack of services can be remedied is for there to be a large-scale, continuing injection of funding. The proposed NDIS is an excellent way of delivering this funding – the only way. It is fair, as it asks the community as a whole to fund the cost of treating disability, rather than leaving the entire burden to fall on the families of the disabled.

There will no doubt be resistance to establishment of an NDIS, because of the cost. Of course, the cost of not establishing such a scheme will in the long run be much greater, when one takes into account the burden on the taxpayer of supporting disabled persons who have not received the treatment they need to become productive citizens, and whose families can no longer cope.

Even in the shorter term, the community generally has become much more aware of the plight of the disabled and their families. Most people we meet know someone with a disability, and more often than not the person with the disability is not receiving the care he or she really needs. There is a massive groundswell of support for real action to provide the disabled with the help they deserve. In the words of journalist and disability campaigner Sue O'Reilly, we're as "mad as hell"- and there are a hell of a lot of us.

Sue and Stephen Ferris